



From the Chief Medical Officer, Sir Liam Donaldson

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Dear Colleague

An integrated approach to human transmissible spongiform encephalopathies (prion diseases): surveillance, health care, public health controls, clinical trials and other clinical research.

The first UK clinical trial of potential therapy for Creutzfeldt-Jakob Disease (CJD) is expected to begin shortly. We need to ensure a high level of patient referral to the trial whilst maintaining the public health surveillance function, and delivery of the care package for patients with this disease.

The responsibility for care and investigation of individual patients remains with the consultant responsible for that patient in consultation with the general practitioner. Nevertheless, the Department of Health is asking the local consultant neurologist, or consultant in other speciality with responsibility for the patient's care, to report to both the National CJD Surveillance Unit and the National Prion Clinic all suspect cases of CJD and other prion diseases. Both the National CJD Surveillance Unit and the National Prion Clinic are able to provide clinical advice about individual patients.

It is essential that local consultants continue to report patient details, with consent, to the National CJD Surveillance Unit for public health and surveillance purposes. In addition, consultants will also wish to ensure that the patient and his or her family, carer or independent representative are put in touch with the national care package co-ordinator, based at the National CJD Surveillance Unit, who can facilitate access to local support services.

Simultaneously, local consultants are asked to report patient details, with consent, to the National Prion Clinic, so that patients can be offered the chance to participate in the PRION 1 trial, should the diagnosis be confirmed

as probable or definite CJD or another prion disease, and also to participate in related research programmes. Completed forms should be faxed to the units, contact details are provided in [Annex D](#). Referring consultants may also wish to utilise the specialist clinical and diagnostic expertise at the National Prion Clinic.

The report to the National CJD Surveillance Unit and the National Prion Clinic should take place on a single form ([attached at Annex A](#)) and must be authorised by the patient or their representative. Patients/families should be provided with a single information leaflet explaining the work of both the National CJD Surveillance Unit and the National Prion Clinic. A copy, produced jointly by the two units, is at Annex B.

[Annex C](#) aims to clarify roles and responsibilities for the reporting, surveillance, diagnosis and care of patients with CJD and other transmissible spongiform encephalopathies, as well as arrangements for public health control measures and research. Contact details are at [Annex D](#).

Actions requested of local clinicians

On encountering patients whom they suspect to be suffering from CJD, or a related prion disease, consultant neurologists (or other clinicians) will:

- ☐ complete the national reporting form and obtain consent from the patient, lead relative or carer/patient representatives;
- ☐ fax or post the completed form, with consent, to the National CJD Surveillance Unit and the National Prion Clinic;
- ☐ advise the patient, carer, or independent representative that staff from the National CJD Surveillance Unit will visit the patient for national surveillance purposes (with their consent). They will also be given the opportunity to participate in research programmes operated by the Unit should they so wish;
- ☐ consider utilising the expertise in diagnosis and management of patients offered by staff at the National Prion Clinic;
- ☐ advise the patient, carer or independent representative that staff from the National Prion Clinic will visit and offer the opportunity to participate in therapeutic trials and/or other clinical research programmes, should they so wish.
- ☐ make available samples of blood and Cerebrospinal Fluid (CSF), and the results of Magnetic Resonance Imaging (MRI) scans to the two units.

Conclusion

Maintaining high levels of public health protection from the risks of vCJD and other prion diseases, ensuring high quality care for patients with the disease,

their families and carers, as well as furthering understanding of prion disease and pursuing the goal of effective treatments for these fatal diseases depend on all individuals and organisations working well together.

This letter and its annexes are intended to clarify and strengthen arrangements to make sure that this happens.

Yours sincerely

A handwritten signature in dark ink, appearing to read 'Liam Donaldson', is centered below the closing 'Yours sincerely'.

SIR LIAM DONALDSON
CHIEF MEDICAL OFFICER